

Introduction

Kirklees Council is working to become dementia friendly with many staff trained as dementia friends and working towards making Kirklees a Dementia Friendly community where members of the public and professionals are well informed and people with dementia can live life to the full.

As we go to print, there are more than 3,000 people diagnosed with dementia in Kirklees, with an anticipated further 1,500+ still coping at home undiagnosed. With an ageing population, this figure is set to rise to more than 7,500 by 2030.

As dementia affects people in many different ways, you and your carers may not know exactly what information you will need in the coming months and years, so we have put together this guide to help you at every stage of your journey. However, there are many comprehensive detailed and specialist factsheets available (a list is at the back) for you to either print yourself at home - or you can ring the relevant organisation and ask for a copy to be posted out to you. We encourage you to build up a set of information which is important to you and your family and to keep it to hand for you to refer to at a later date.

All contact details were correct at the time of going to print. We hope you find the information helpful and a good starting point for finding the right support and help you need. Kirklees Council do not endorse or promote products and services - this guide is for information sharing.

To get help, information or advice on dementia from Kirklees Council, please ring: Gateway to care, telephone **01484 414933**.

Further information is available on our website: www.kirklees.gov.uk/dementia

Being diagnosed with dementia can be an anxious time for both you and for your family and friends. There are many questions to answer and you will feel uncertain about the future. It is very important that you know how much support and expertise is available to you and your carers and how to get that help when you need it the most.

This booklet is to help you to start thinking about some of the issues that come with dementia.

Some of the help available can be accessed on the internet via a computer. If you are reading this on a computer with internet access, by pressing CTRL and clicking on the words which are **bold black and underlined**, these will take you directly to the relevant page on the internet, but there is a list provided at the back of this booklet. If you do not have a computer, you can use one at a library or at a Neighbourhood Learning Centre. Whichever way you choose, please do your research - there is much information available to help you from many organisations and we only refer to some of the excellent sources of information available to you.

What is dementia?

Whilst dementia is more common in older people, it is not a normal part of ageing and there are many things we can do to reduce our chances of developing the disease.

The term 'dementia' is used to describe a set of symptoms which cause the ongoing decline of the brain.

Dementia is progressive, meaning some symptoms may get worse over time. You may begin to find coping with day-to-day tasks more difficult, have problems communicating and may show changes in your mood/personality. This can be frustrating and frightening for you and for your family and friends.

We all accept a certain degree of forgetfulness as we get older but with dementia, memory loss is more serious than forgetting things occasionally. It starts to interfere with everyday life. Dementia isn't always diagnosed early and the true symptoms aren't particularly well known and will be individual to each person.

However, we do know that early diagnosis is vitally important and can make long term planning easier for you and enable you to be actively involved in that process. There is evidence that current medication for dementia may be more effective when taken at an early stage. It can also help in the management of other symptoms associated with dementia such as depression.

What are the symptoms?

If you are showing three or more of these **symptoms**, which are interfering with your daily life, visit your doctor:

- Poor concentration
- Memory loss, for example names of people and places, events that have taken place
- Extreme tiredness
- Asking the same questions repeatedly
- Mood swings or aggressive behaviour
- Confusion about the time of day
- Losing things or putting things in inappropriate places
- Getting lost in previously familiar places
- Difficulties understanding people and finding the right words
- Repetitiveness (doing the same task over and over)

There are several diseases and conditions that result in dementia. These include:

- **Alzheimer's disease** - The most common cause of dementia. As the disease progresses, the chemistry and structure of the brain change, leading to the death of brain cells.
- **Vascular dementia** - Narrowing of the small vessels bringing blood to the brain.
- **Dementia with Lewy bodies** - This form of dementia gets its name from tiny abnormal structures that develop inside nerve cells. Their presence in the brain leads to degeneration of brain tissue. This type shares some characteristics with Alzheimer's and Parkinson's disease.
- **Fronto-temporal dementia (including Pick's disease)** - In fronto-temporal dementia damage is usually focused in the front part of the brain.
- **Korsakoff's syndrome** - This type of dementia is usually associated with heavy **alcohol** consumption over a long period of time.

There are other types and causes of dementia. Please ask your doctor for more detailed information or you can contact the National Dementia Helpline - telephone **0300 222 1122**.

What risk factors affect whether I may develop dementia?

Over recent years, huge steps have been made in understanding what factors contribute to developing dementia. Dementia does not discriminate and anyone can develop the disease, but the following **factors** may contribute:

Who gets dementia?

Anyone can develop dementia – it is not restricted to age, gender, ethnicity or social status. However, some groups are statistically more likely to develop it. Someone developing dementia aged under 65 is considered to have 'early onset' dementia. See **Age UK - Living with early stage dementia**

- **Age** - you are more likely to develop dementia when you get older, especially if you have high blood pressure or have a higher risk of other genetic diseases.
- **Genetics** - in the same way as heart problems, Alzheimer's and Huntington's disease can be passed down in generations in a family, so can dementia.
- **Medical history** - having current conditions or having experienced certain conditions in the past may contribute to developing dementia, such as Multiple Sclerosis, Down's Syndrome, Diabetes, HIV and Metabolic Syndrome.
- **Our general lifestyle** - poor diet, lack of exercise and excessive alcohol/drug consumption can all increase the chances of developing the disease.
- **Parkinson's disease** - people with Parkinson's disease have a higher-than-average risk of developing dementia, although most people remain unaffected. Symptoms vary from person to person.

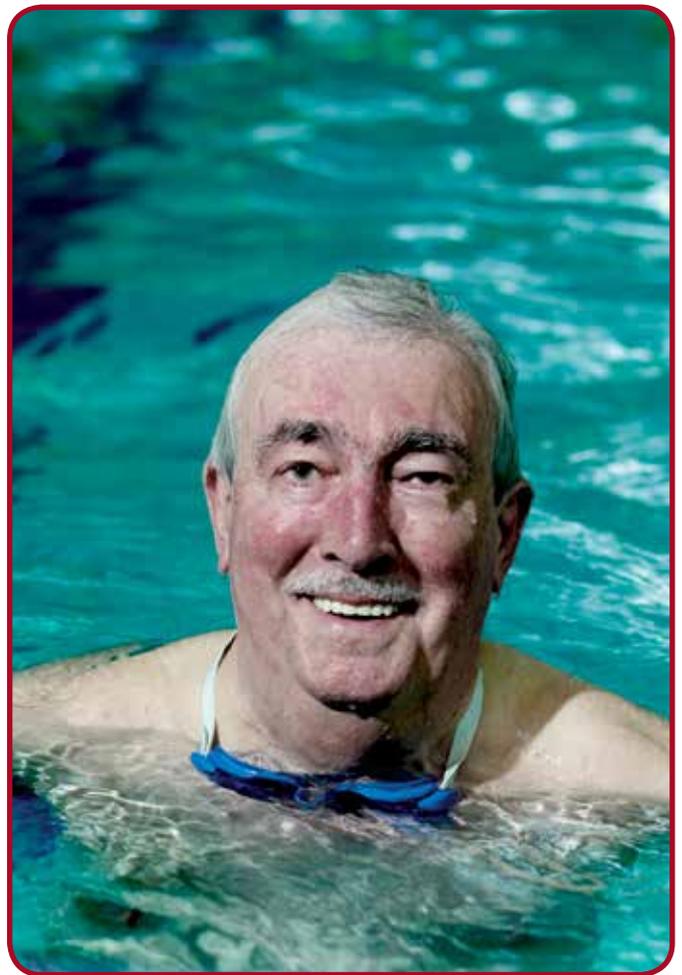
What can we all do to reduce the risk of developing dementia?

Whether you are genetically at risk of developing dementia or not, there are steps you can take to reduce the risk of the onset of dementia.

Keep active - you don't have to go to a gym - there are many different types of exercise and activities, each bringing its own benefits: from swimming, walking, tennis, bowling, aerobics or even gardening and cleaning the house. It all adds up to increasing your levels of fitness and giving you a feeling of well-being. See our community factsheets to find out what is going on in your area and our factsheet **Physical activity opportunities** which explains Steps for Life. This is an exercise referral programme for people with dementia or you can telephone **01484 234092** for more information.

Eat well - a balanced diet is essential. Eating plenty of fresh fruit and vegetables every day is vital for your brain and body as the nutrients they contain help fight disease. Oily fish is also an important part of a healthy diet as it contains omega 3 fatty acids.

Be aware of your alcohol intake - and remember the safe recommended limits of 3-4 units per day for men and 2-3 units per day for women, with at least two alcohol free days per week. Speak to your GP for advice or look at www.nhs.uk/Tools/Pages/Alcoholcalculator.aspx for a calculation and advice.



Stop smoking - its harmful effect on the vascular system increases the risk of developing vascular dementia.

Test your brain - keep your brain active. Crosswords, puzzles, reading and quizzes all contribute to stimulating your brain, which is essential for good mental health.

Get out and about - socialising and making new friends helps to maintain physical and mental wellbeing. Joining clubs/groups or volunteering is a good way to keep active and gives you a chance to have a chat with someone different. You could even run your own support group.

Keep an eye on your blood pressure and cholesterol levels - visit your doctor regularly to have these checked.

Get plenty of sleep.

For more information look at the NHS's online self-help website: NHS Choices or telephone 111. Remember: What's good for your heart is good for your head.

The five things everyone should know about dementia

- 1.** Dementia is not a normal part of ageing
- 2.** Dementia is caused by diseases of the brain
- 3.** It is not just about losing your memory
- 4.** It is possible to live well with dementia
- 5.** There is more to a person than dementia

Take a look at the Alzheimer's Society information for more details on the **five things everyone should know about dementia.**

Kirklees Alzheimer's Society is located in the centre of Huddersfield and offers support to anyone who has received a diagnosis of dementia or may be worried about their memory. Their team are able to support you to access local services and a wide variety of information, including factsheets, information booklets and information for people who are visually impaired or whose first language is not English. They can signpost/refer you to other local and national support services and will tailor all of their support to your individual needs. You can contact them in relation to any dementia diagnosis or if you are worried about your memory telephone **01484 429865** or by email on **C&K.Services@alzheimers.org.uk**

Getting a diagnosis

Early diagnosis can make all the difference. Early use of medication may help delay symptoms, as well as improving those which already exist.

If you suspect that you or someone you know is showing symptoms of dementia, you should contact your doctor as soon as possible. Your doctor may diagnose dementia or may refer you to a specialist such as the Kirklees Memory Service.

A diagnosis will usually be made depending on how you are affected, family history and psychological changes. Some people aren't always aware of the changes and do not realise that they need help. It is useful to take someone with you to see your doctor and to any clinic appointments who can help answer questions and take notes for you to refer to at a later date. Take a list of questions with you.

Kirklees Memory Service

This service provides assessment, diagnosis and consideration of possible treatment options. Referrals to the service will usually come from your doctor. This is to ensure that the referral is suitable, that other illnesses have been ruled out and to start investigations. The service includes Nurses, Occupational Therapists, Doctors, Admiral Nurses and a team who specialise in younger people with dementia (Crowlees).

The service may arrange tests of their own to help diagnosis and these can include:

- Memory tests
- Questions relating to language and simple mathematical skills
- A physical examination and laboratory investigation (eg blood and urine tests)
- A computerised tomography (CT) scan or a magnetic resonance imaging (MRI) scan

If a treatment is prescribed, the service will monitor your progress to ensure you are stable on your medication and you will then be discharged back to the care of your doctor who will undertake a regular review of your medication and support.

You and your carer should never feel awkward about asking questions. It is important you understand what is happening at every stage and if you don't understand the answer you are given, ask again for it to be explained to you. Your doctor is there to help you.

What if you don't get a diagnosis of dementia?

It is possible that your doctor may not diagnose dementia. For some people this will be a relief but to those who know that something is not right, this will be a worrying and frustrating time. If all appropriate investigations have been done and you are still worried, ask your doctor to repeat the tests after 6-12 months to look for a change.

You've been diagnosed with dementia... what next?

Please remember that you are not alone. Many people live a fulfilling and happy life after a diagnosis of dementia.

Information is vital to you continuing to live a good quality of life. Find out as much as you can about all the support that is available to you and to your family and carers. It's always a shock to be diagnosed with any condition and the long term implications of dementia can make it a daunting and frightening prospect. You may go through a variety of emotions. However, there may be relief that a diagnosis has actually been made, which means you can start to make plans and take positive steps to continue to live your life to the full.

It is important to be able to share your feelings, whether you have been diagnosed with dementia or are a carer. This is a time when your family and friends can play a very important role in helping you come to terms with the diagnosis. It's also important to recognise that your family will often be experiencing very similar emotions too and will need support and advice before they can, in turn, support you.

You need to make sure that you look after yourself and keep yourself healthy and safe, eat well and have regular health check ups from your doctor, dentist, optician etc.

Take a look at the Alzheimer's Society factsheet '**After diagnosis**' or telephone them for a copy of their booklet

What your diagnosis means for you

Medication can play a key role in controlling the behavioural and psychological symptoms of dementia, particularly when it has been diagnosed early. Types of drugs include:

- Anti-dementia medication - useful in delaying the progression of dementia and there is now evidence of them controlling aggression and agitation.
- Antipsychotics - used as a short term option in rare cases.
- Antidepressants – these may help in controlling the depressive symptoms in dementia.

If medication is considered the only option, it can take a few attempts with different brands of drugs before finding the right balance. Always take medication exactly as prescribed by the doctor and you should not stop taking them without talking to your doctor first. Non pharmacological interventions could also be considered. See the section on Health and Wellbeing later in the guide.

Keep medicines safe - away from vulnerable people and children.

Take a look at the Alzheimer's Society factsheets:

Drug treatments for Alzheimer's disease

Drugs used to relieve behavioural and psychological symptoms in dementia

Once you feel able to discuss matters more openly you will need to make some decisions about your future. These decisions should include:

- **Care** - who will care for you as dementia progresses and what would you like that care to look like?
- **Finance** - what is your financial situation? Will you need to give up work?
- **Accommodation** - where will you live in the short/long term and will you be able to afford to continue living in your own home if you are not working?

